



American Association of People with Disabilities

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**Hearing of the Senate Health, Education, Labor, and Pensions Committee  
“Community Services and Supports: Planning Across the Generations”**

**July 10, 2007**

**Testimony of Andrew J. Imparato  
President and Chief Executive Officer  
American Association of People with Disabilities (AAPD)**

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Chairman Kennedy, Ranking Member Enzi, and Members of the Senate Health, Education, Labor, and Pensions Committee:

Thank you for giving me the opportunity to testify today regarding the very important topic of community living and long-term services and supports. My name is Andrew J. Imparato, and I am the President and Chief Executive Officer of the American Association of People with Disabilities (AAPD), a national non-profit, non-partisan membership organization promoting the political and economic power of the more than 50 million children and adults with disabilities throughout the U.S. With more than 100,000 members, AAPD is the largest national cross-disability membership organization in the country. I am very glad to provide my testimony today on behalf of not only AAPD but also three other national, cross-disability, non-partisan membership organizations – ADAPT, the National Council on Independent Living (NCIL), and Self Advocates Becoming Empowered (SABE) – all of which also share the goals of self-determination and full participation for our community in all aspects of society.

NCIL is the oldest cross-disability grassroots membership organization run by and for people with disabilities, advocating for independent living and the advancement of people with disabilities through consumer-driven advocacy. ADAPT is a national membership organization focused on changing the long-term care system through achieving adequate attendant services in the community and ensuring that individuals who want to leave nursing homes and other institutions to live in their own homes and communities can do so. SABE is committed to ensuring that people with disabilities are treated as equals and are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves.

As a former counsel to this Committee’s Disability Policy Subcommittee between 1993 and 1994, I have had the pleasure of working closely with bipartisan members and staff on this Committee, and I very much appreciate your commitment to civil rights, self-determination, and full participation of children and adults with all types of disabilities in all aspects of society. My testimony is grounded in my professional experience as a disability rights lawyer and policy advisor and my personal experience as a person with bipolar disorder or manic depression.

Also, as a Senate appointee to the bipartisan Ticket to Work and Work Incentives Advisory Panel, I chair that Panel’s committee that has been tasked with developing a new model for providing supports and services to people with significant disabilities. Our new model, which we are calling a “national employment investment strategy,” is grounded in higher expectations and more timely investments that will provide a strong return over the lifespan of an individual with a disability. We believe that timely investments will result in cost savings to the federal government, higher quality of life for people with significant disabilities, and a new skilled

workforce that can help mitigate labor market shortages that are projected over the next several decades.

Perhaps the most important point I could make this morning is that every American is a stakeholder in today's topic. There are currently 10 million Americans in need of long term services and supports, and that number is expected to rise to nearly 15 million by 2020.<sup>1</sup> These individuals are male and female, adults and children, with a broad range of disabilities represented. This is in no way a static population.

Disability civil rights laws start with the recognition that disability is a natural part of the human experience that in no way should limit a person's right to make choices and participate fully in all aspects of society. Any person at any time can acquire a disability. Some people acquire disability as they age. By 2030, when the youngest baby boomers reach retirement, the population of those age 65 and older will nearly double to 71 million, comprising 20 percent of the American population.<sup>2</sup> Some people acquire their disabilities through birth; some through accident or injury; some through illness. Still others acquire disability while putting their lives on the line for our country. Traumatic brain injury has become the signature wound of the Iraq-Afghanistan wars, with estimates as high as 60-70% of all wounded returning vets having TBI.<sup>3</sup> This unprecedented population of disabled soldiers and veterans is expected to have ongoing needs for long term services and supports over the course of their lifetimes, with some recent reports suggesting the cost of care could be as much as \$14 billion over the next 20 years.<sup>4</sup>

Given the diversity of the disability population across the age spectrum, our country requires a long-term care system that affords people real choice in how and in what environment they will receive the supports they need to live. This means a system built to work for *all* people without regard to age or disability. One that begins with the assumption that adults with disabilities want to work, children with disabilities want to learn and play with their neighborhood friends, and the vast majority of individuals in need of long-term services and supports would rather receive those supports at home with family and friends. One that looks holistically at people with disabilities and understands that long term care should be integrated with acute care services; that personal care attendants are a reasonable workplace accommodation; and that people should have freedom in choosing where to live and not be forced into certain types of housing in order to qualify for the supports they need to survive. Only a long term care system that is comprehensive in scope could satisfy the existing as well as impending demand for long term care that moves us away from our long legacy of warehousing people with disabilities – simply maintaining them so they can survive another day – and toward *investing* in them, with an expectation of return. Choice and control should be at the foundation of any comprehensive reform. Sadly, this vision of comprehensive reform is the complete opposite of what we have in place today.

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<sup>1</sup> Kaiser Family Foundation (July, 2006). *Medicaid and long-term care services*. Washington, CD: Kaiser Commission on Medicaid and the Uninsured; Feder, J., Komiser, H.L., & Friedland, R.B. (June, 2007). *Long-term care financing: Policy options for the future*. Washington, DC: Georgetown University Long-Term Care Financing Project.

<sup>2</sup> Alliance for Health Reform (March 2007) *Issue Brief: Long-Term Care Partnerships: An Update*

<sup>3</sup> Institute of Medicine, the National Academies, *Evaluating the HRSA Traumatic Brain Injury Program*, Washington, D.C.: The National Academies Press, Eden, Jill and Rosemary Stevens, Editors, 2006, p. 41.

<sup>4</sup> "One Soldier's Struggle with the Iraq War's Trademark Injury," *Stanford Medicine Magazine* (summer 2007), referencing a report by Linda Blimes of Harvard's Kennedy School of Government and Joseph Stiglitz, Ph.D. of Columbia University.

Our current system of long-term care dates back to 1965, when the Medicaid and Medicare programs were first created.<sup>5</sup> Not surprisingly, given the origins of these programs, the system continues to exemplify the historically low expectations society has had for people with disabilities for decades. With the expectations for us so low, the mission of the old system was and remains to this day focused on simply maintaining people with disabilities in nursing homes, other institutions, and back rooms, outside of view and away from the mainstream. In 1965, people with disabilities were largely out of sight, because society was inaccessible, both literally and attitudinally. In 1965, states still had involuntary sterilization laws for people with disabilities. Curb cuts were few and far between. There was no Americans with Disabilities Act (ADA). It is 42 years later, and it is an abomination that hundreds of thousands of people with disabilities remain trapped in a broken system that steals lives, saps peoples' spirit, and enriches service providers at the expense of disabled people and their families.

The existing long term care system in this country is shouldered almost entirely by family caregivers and public programs provided in institutional settings, in overly medical ways that are often unnecessary and needlessly expensive. Private insurance for long term care comprises only 3% of long term care spending, and a recent study showed that as few as 10% of Americans can even afford a quality, private long term care policy.<sup>6</sup> The rest of the population gains access to the existing public system by "spending down" to a poverty level which triggers their eligibility for Medicaid and in turn, the supports they need.

The government as well as the private sector has failed Americans in planning for the onset of disability. *Everyone* is paying for the inadequate, problematic system, and we are paying big. Long-term care represents a massive financial imposition on families and states. Approximately \$160 billion was spent on long term care in 2004, with Medicaid financing approximately 42% of that figure.<sup>7</sup> Nearly one third of Medicaid's entire budget of \$300.3 billion is spent on long term care annually – that's approximately \$94.5 billion dollars.<sup>8</sup> Sixty-three percent of that \$94.5 billion goes directly into institutional care, despite the fact that the vast majority of those needing long term care would prefer to get these services in-community.<sup>9</sup> Research out just last year from the University of California San Francisco and the University of Maryland estimates that when compared with Medicaid institutional care, home- and community-based waivers created a national average saving of \$43,947 per participant.<sup>10</sup> As an example, the national average per-participant expenditure for a nursing facility waiver was \$15,784 – 63% lower than the \$42,292 national average per-participant expenditure for a nursing facility.<sup>11</sup> Even more significant savings were reported for Medicaid waiver participants with an "Intermediate-Care Facilities for the Mentally Retarded / Developmentally Disabled" (ICF-MR/DD) level of care (70% lower expenditures than ICF-MR/DD expenditures) and waiver participants with a hospital

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<sup>5</sup> Hearing on Long-Term Care and Medicaid: Better Quality and Sustainability by Giving More Control to People with a Disability Before the Subcommittee of the House Committee on Energy and Commerce, 109<sup>th</sup> Cong. (April 27, 2005) (testimony of Mark B. McClellan, MD, Ph.D., CMS Administrator, Centers for Medicaid and Medicare Services).

<sup>6</sup> *Id.*

<sup>7</sup> Kaiser Family Foundation (July, 2006). *Medicaid and long-term care services*. Washington, CD: Kaiser Commission on Medicaid and the Uninsured.

<sup>8</sup> Numbers taken from a report from Medstat Group, Inc., with data taken from CMS 64 reports submitted by states and compiled by ADAPT.

<sup>9</sup> *Id.*

<sup>10</sup> Kitchener, M., Ng, T., Miller, N., Harrington, C. (2006). Institutional and Community-Based Long-Term Care: A Comparative Estimate of Public Costs. *Journal of Health & Social Policy*, 22, 32-33.

<sup>11</sup> *Id.*, at 38.

level of care need (84% lower than hospital expenditures).<sup>12</sup> Despite these findings, what is guaranteed in the existing public system is a more expensive service that people do not want, while the more cost effective service individuals would rather use is not guaranteed. How is this morally justifiable or fiscally responsible? Why are we allowing this to continue?

Last September, I traveled to Nashville along with representatives from the U.S. Department of Health and Human Services Office on Disability and the National Council on Disability to meet with a large group of survivors of nursing home and other institutions. All of these individuals had been locked away and had portions of their lives stolen despite their strong desire to live in their homes and communities. Their testimony, which lasted almost 7 hours, was submitted to the Medicaid Commission and is a part of the public record. The testimony also appears as an appendix to this written testimony. As I sat and listened, person after person, men and women, of all ages and races, gave accounts of being left in their own urine and feces, tied to their beds, raped, burned, deprived of food, put in bathtubs of cold water – sometimes as a result of neglect but most often as retaliation for complaining about their inhumane living conditions. It was particularly striking to me how many of the witnesses talked about being forcibly medicated by facility staff as a way to keep them quiet. As a person with a psychiatric disability, I am very aware of how people get forcibly medicated in mental hospitals—a practice which I view as a violation of those individual's basic human rights. Based on the frequency of the testimony in Nashville, it appears that forced medication is a tool used by institutions of all kinds as a way to quell dissent and sap people's spirits. Human rights violations are taking place *every day* in *every state* in this country, and Congress has repeatedly failed to take decisive action to end the abusive and unnecessary costs of institutional care.

Which of you, were you to acquire a disability tomorrow that required long-term services and supports, would favor living in a nursing home or other institution, slowly selling off your life as you know it to live in conditions in which you forfeit your freedoms? Which of you would feel any degree of comfort in the knowledge that your loved one was forced to live in an environment with a legacy of human rights abuses?

We have, in addition to this testimony, submitted a 10-minute DVD to the record compiled by ADAPT, which highlights the testimony of these nursing home survivors in Nashville. Each Senator should have also received a copy of this DVD in advance of today's hearing. Many have been quick to say that all we need is "nursing home reform," but nursing home reform is *not* the answer, and we hope that these peoples' stories will help Senators to understand that. What we need is comprehensive reform that focuses on the community as the first and best option for long-term services and supports.

Although most people think that nursing homes are nice places in which people receive excellent care, thousands of our organizations' members are telling us that their own experiences in nursing homes have been anything but helpful and compassionate. These testimonials do not represent a handful of individuals. According to data from the Centers for Medicaid and Medicare Services, there are over a quarter of a million people living in nursing homes to receive long-term care who want out! Chairman Kennedy, in your home state of Massachusetts, according to data from a CMS report regarding discharge potential and resident preferences to return to the community, as of 2003, there were 7,947 people living in nursing

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<sup>12</sup> Id., at 39.

homes in Massachusetts who want out but are “stuck” by the system Congress created.<sup>13</sup> Ranking Member Enzi, in your home state of Wyoming, there were 2,415 individuals as of 2003 living in nursing homes and over 1 in 5 of them – 532 of them – said they wanted out.<sup>14</sup> These are people who not only *prefer* to live in the community; many of these folks have unequivocally testified that they would rather die than suffer the indignities and loss of independence associated with institutionalized care.

Even still, many remain convinced that many of the individuals who want out of the nursing homes are people who could not survive outside of them. This is simply untrue. Not only do these people want to move out of nursing homes, they *can*, provided they receive the appropriate services and supports to make it happen. Moving someone out of a nursing home and providing the adequate level of supports to foster their independence is not about charity – this is a matter of civil rights and freedom.

Today, in America, the land of the free, we have over a quarter of a million people in captivity – living in institutions for the sole reason that the federal money stream for the services they require only provides services in those environments.<sup>15</sup> Only approximately 11% of adults with developmental disabilities receive formal residential long-term services, and of those who do receive services, 32% reside in institutional settings.<sup>16</sup> Today, in America, hundreds of thousands of people with disabilities are on waiting lists for personal attendant services. Over 53,000 individuals with developmental disabilities alone are on formal waiting lists for residential services across the country – and as high as that number is, we can trust it is grossly understated because states often do not keep formal lists for fear of lawsuits.<sup>17</sup> In many states, unless you’re being abused, severely neglected, or your informal family caregiver dies, you are simply not going to access community services.

Of those individuals who are fortunate enough to find provision of long-term care outside of a nursing home or other institution, many are receiving personal attendant services through an informal family caregiving arrangement. In fact, 85% of the 22 billion hours of personal attendant services provided each year are unpaid, exacting an enormous and disproportionate toll on women who represent 69% of all caregivers, nearly half of whom live below twice the poverty level.<sup>18</sup> Although the economic value of informal caregiving is estimated to be over \$306 billion a year, personal attendants rarely make a living wage and seldom have access to health benefits, although their jobs are characterized by a high rate of occupational injuries.<sup>19</sup> What will happen

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<sup>13</sup> Centers for Medicare and Medicaid Services (December 31, 2003), Minimum Data Set (MDS) Numbers for Question Q1a, available at <http://www.cms.hhs.gov/states/mdsreports>.

<sup>14</sup> *Id.*

<sup>15</sup> Numbers taken from a report from Medstat Group, Inc., with data taken from CMS 64 reports submitted by states and compiled by ADAPT, July 2006.

<sup>16</sup> Braddock, D., Hemp, R., Rizzolo, M. C., Coulter, D., Haffer, L., & Thompson, M. (2005). *The state of the states in developmental disabilities*. Boulder: University of Colorado, Coleman Institute for Cognitive Disabilities.

<sup>17</sup> Prouty, R., Smith, G., & Lakin, K. C. (2005). *Residential services for persons with developmental disabilities: Status and trends through 2004*. Minneapolis: University of Minnesota, Research and Training Center on Community Living/Institute on Community Integration.

<sup>18</sup> LaPlante, M.P., Kaye, S., Kang, T., & Harrington, C. (2004). Unmet need for personal assistance services: Estimating the shortfall in hours of help and adverse consequences. *Journal of Gerontology*, 59B, S98-S108.

<sup>19</sup> Arno, P. S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs*, 18, 182–188; Kaye, S. (2007) “Trends in the PAS Workforce: Where Have We Been and Where

when these caregivers require care of their own or pass away? Many families are plagued by these currently unanswerable questions, because there is absolutely nothing comforting about the system as we know it today. Of those individuals with disabilities receiving home and community-based supports, over 21% report unmet needs in their personal assistance services.<sup>20</sup> Such individuals with unmet needs are more likely to experience inadequate diet and nutrition, discomfort, isolation, deterioration in health status, and –bitterly ironically – institutional placement and/or increased disability – and so the cycle continues.<sup>21</sup>

It has been eight years since the Supreme Court ruled in *Olmstead v. L.C.* that the ADA prohibits the unjustified segregation of people with disabilities through official state action and requires states to administer services in the most integrated setting possible, appropriate to the needs of the individual. Still, there is no change in the Medicaid statute, eight years later. One of the major impediments to *Olmstead* enforcement is states' budget shortfalls. Since nursing homes are an entitlement, and since the optional program ICF-MR have been selected by every state but Arizona, states *must* fund those services. However, community services remain an optional component, and so if and when they are funded, it's with whatever "leftover" money there is (or is not).

President Bush's New Freedom Initiative included a Money Follows the Person demonstration project to encourage states to try the idea of letting Medicaid dollars follow the person to the location in which they desire to receive their services and supports, thereby integrating people with disabilities into the community. Since January, CMS has awarded 31 states and the District of Columbia demonstration grants for alternatives to institutional care. As a result, 27,000 individuals who want to live in their communities will be transitioned into them from out of institutional care, made possible by an enhanced federal Medicaid match.<sup>22</sup> States save money, the federal government saves money when spending on community care rather than institutional care, and people with disabilities can rejoin their family and friends in the community.

It has been 13 years since Newt Gingrich introduced MiCASA in the same spirit of the Money Follows the Person demonstrations. MiCASA has evolved and was recently renamed the Community Choice Act, introduced as S.799 by Senators Tom Harkin and Arlen Specter. Thirteen years later, there is still been no markup. Although every state that receives Medicaid must provide nursing home services, community-based services remain optional. The Community Choice Act is a bill that puts highly personal choices back into the hands of those directly affected. It is a bill about real choice. The bill gives equal access to community-based supports for those eligible for nursing home and ICF-MR services and provides enhanced federal matching funds to help states offer greater flexibility in giving citizens what they want. The Community Choice Act creates a national program of community-based attendant services and builds on the Money Follows the Person programs, allowing the Medicaid dollars to follow the person wherever the individual or his or her representative chooses to receive necessary services and supports. Rather than make a new entitlement, the Community Choice Act makes the existing one more flexible. It has been 13 years, and it is time this bill passed into law.

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are we Going?" presentation at "Meeting the Nation's Needs for Personal Assistance Services State of the Science Conference," April 27, 2007, Washington, D.C.

<sup>20</sup> LaPlante, M.P., Kaye, S., Kang, T., & Harrington, C. (2004). Unmet need for personal assistance services: Estimating the shortfall in hours of help and adverse consequences. *Journal of Gerontology*, 59B, S98-S108.

<sup>21</sup> *Id.*

<sup>22</sup> CMS data, compiled by ADAPT.

Researchers have re-estimated the costs of a mandatory Home and Community-Based personal assistance services benefit under Medicaid to be between \$1.4 and \$3.7 billion per year, versus a prior CBO estimate nearly a decade ago in the \$10-20 billion range.<sup>23</sup>

The Direct Support Professionals Fairness and Security Act, H.R. 1279, introduced by Rep. Lois Capps, would also help to improve the sustainability of the long-term care landscape. The Act would amend title XIX of the Social Security Act to provide states with additional funds by which to increase wages paid to direct support professionals who provide assistance to people with disabilities under the Medicaid program to eliminate the current wage gap. The Act would also require study of recruitment and retention of direct support workers. Although increasing wages should never be at the expense of the consumer through cutbacks on attendant services hours, increasing wages of long-term care attendants is one way in which the pool of available workers could be increased.

While these bills are vital in reforming Medicaid, which remains a dumping ground that provides inadequate care to people who have already been failed by every other system, their passage alone will not deal with the fundamental problem of the general population's failure to plan for the onset of significant disability. The Community Living Assistance Services and Supports Act, or the "CLASS Act," introduced today in both the House and the Senate, creates a new program that can take pressure off Medicaid and enable people to avoid being forced into poverty. By encouraging people to begin planning and saving for the onset of a disability from the moment they begin working, it creates an alternative funding source to Medicaid for the provision of long-term services and supports that does not require people to impoverish themselves or stop working in order to gain access to the supports they need. It allows the individuals who have saved for the onset of disability spend the benefit however they feel is most appropriate toward their long-term needs, be it a housing or transportation modification, assistive technology, or personal attendant services. The CLASS Act takes a realistic and responsible approach to disability, and like the Community Choice Act, it's about *real choice*.

At AAPD, ADAPT, NCIL and SABE, we want to see these topics become a leading 2008 election issue anytime candidates discuss their civil rights platforms or health care agendas, so that whoever comes into office in 2009 is committed to seeing these changes through. Many Americans languishing today in institutions all over this country are running out of time.

This is a crisis, and it should be handled like a crisis – with urgency and full governmental support. Unless the government steps up to address these concerns in a bipartisan, comprehensive way, we are going to see this crisis get even worse. Congress *must* ensure that the principles undergirding the new infrastructure are based on *real* consumer choice and *meaningful* dialogue with stakeholders, including individuals with disabilities. As Congress considers reform of the long term care system, it will be tempting to make piece-meal change, but the system will continue to falter unless we approach reform with a comprehensive lens. We cannot afford to talk about long-term care without also talking about personal attendant services, attendant recruitment and wages, the integration of long-term and acute care services, integrated housing, accessible transportation, and employment accommodations. We can't afford to address each of these topics in isolation from the others, or we will be having this same conversation again in ten more years because the system will still not work. Comprehensive

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<sup>23</sup> LaPlante, M.P., Kaye, H.S., & Harrington, C. (in press). Estimating the expense of a mandatory home- and community-based personal assistance services benefit under Medicaid. *Journal of Aging & Social Policy*.

reform would entail finding a mechanism to take all these funding streams and mold them into a comprehensive, focused long-term services and supports system that places control in the hands of the consumer not the bureaucrats.

We call on Congress to demonstrate leadership and take the first steps down a path of comprehensive reform of long-term care. We urge Congress to pass the Community Choice Act, which would reduce the institutional bias in Medicaid. Pass the Direct Support Professionals Fairness and Security Act, which would provide funds to States for purposes of increasing the wages paid to direct care workers. Pass the Community Living Assistance Services and Supports Act (CLASS Act) as an alternative to the Medicaid "poverty trap." Direct HHS to enforce the integration mandate recognized by the Supreme Court in the 1999 *Olmstead* decision, and encourage CMS to create incentives for discharge planners. Passage of these bills and work on these programs will not "cure the crisis," but it will go a long way in building the necessary groundwork from which to structure future reform.

Senators Dodd, and Clinton, Brown, and Kennedy, thank you for your co-sponsorship of the Community Choice Act. And thank you all again for providing me this opportunity to testify. I welcome the opportunity to answer any questions that you may have at this time.

**Attachments:**

Appendix A

ADAPT "No More Stolen Lives" DVD